

**STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
November 6, 2017 – 2:00 PM
Smyrna Rest Area, Smyrna**

PRESENT: Ann Phillips, Chair; Linda Brittingham, Christiana Care Health System; Andrew Burdan, Tri BIAD; Tammy Clifton, DVR/BIAD; Vanessa Deloach, DDDS; Donna Dixon, Bayhealth Neurosurgery; Katie Freeman, DSCYF/DPBHS; Chris Malaney, Peach Tree Acres; Dale Matusевич, DOE; Nancy Ranalli, Easter Seals; Ron Sarg, DCVA/MOAA; Jamila Waigwa, DSAAPD; John McNeal, Staff; and Jo Singles, Support Staff.

CALL TO ORDER

Ann called the meeting to order at 2:10 pm. Everyone introduced themselves.

ADDITIONS/DELETIONS TO THE AGENDA

- TBI Data Bank

APPROVAL OF MINUTES

Vanessa made a motion to approve the October 2, 2017 minutes. The motion was seconded by Tammy and approved as submitted.

BUSINESS

Vice-Chair Vacancy

John stated that two people were nominated—Jody Hougentogler and Sharon Lyons. Jody had tried to set up a conference call with Ann and John to get more specific information about the requirements for Vice-Chair, but John had to cancel the scheduled time and the other times did not work out. John hoped that someone would step forward at today's meeting. Jody did not want to take it away from someone who seems interested but wants additional information before making a commitment. John will check on Sharon's interest. Katie suggested that Jane may be interested in serving, but the timeframe for her to commit as a member is unknown at this time. This will be tabled until the January 8th meeting since we do not traditionally meet in December. If anyone is interested in serving as Vice-Chair to send an email to Jo. John clarified that voting has to take place at the meeting. Suggestion was made to have a small write-up on the people who are nominated and some bios have been submitted.

Bios of Committee Members

Seven Committee members have submitted their bios. Once all have been collected, they will be distributed to Committee members. Ann noted that this information will be helpful when looking for resources or knowledge in a certain area. Bios can be submitted in any format, either a resume or job duties that are related to brain injury. Ann asked that Committee members send their bios to Jo before the next meeting. Jo will send an email reminder to Committee members.

Priorities – Path Forward

Jo stated that the voting showed that #2 Priority is now #1 Priority and Priority #1 is now #3 based upon votes received. Jo displayed the chart with voting. Ann read over Debbie's submission—her #1 Priority is #3 Priority (Goal 2: Promote & advocate for laws, regulations, policies, services and funding to effectively serve the needs of people with brain injuries and their families.). John commented that we should work concurrently on the Priorities instead of just #1. He added that some of the Goals and Objectives have been achieved. Debbie added: Identify for and influence legislative and federal/state funding opportunities (how do we get grants and waivers); influence state government at the DHSS level and at the DMMA level to give brain injury a better seat at the table for funding programs; Identify and influence the state agency that should submit to the federal government any grants (DPH?). Debbie stated that the #2 Priority should be the Brain Injury Registry (Goal 2 of old Priority 2) and that #3 Priority is the old #1 Priority (now #2): Debbie noted that the federal government under the Fiscal Year 2018 Budget restructuring proposes to combine, DDS, TBI and ILC (Independent Living Council) and to give the combined group less money. Also, there has not been a TBI grant for 10 years. Sharon had also submitted her choices, being to improve data collection. Ann wanted to give anyone who did not submit their vote a chance to vote during the meeting. Ann reviewed the original document with the Priorities. Several comments were made about getting calls from the public saying that they do not know where to get help. Ann commented that we want to be more effective. No additional votes were cast.

The new #1 Priority is: Provide a network to identify and facilitate acquisition of enhanced resources. Goal 1: Facilitate the ready availability of information on resources and services useful to persons with brain injury and their families. Objective 1.1: Promote the facilitation of the availability of care coordinators/specialists with expertise in public and private brain injury resources. Chris spoke about the new initiatives by Peachtree. In the spring, they plan to break ground on another 78-bed facility, including a day habilitation center. They currently have 20 beds and also have about 15 people in day habilitation from the community. There will be a phase 2 plan which will add 38 beds (hopefully skilled nursing). The funds for these clients (residential and community) come from the HCBS (Home & Community Based Services) Waiver. Katie suggested compiling all this good information about available services. She added that it could be as simple as a blurb in an email. Ann suggested getting general information and then adding specifics later. This would be a good resource to have. She added starting with a list of programs we know. Suggestion was made that the BIAD be the hub. Andrew commented that creating this list would let us know what areas need more services. These resources could be distributed when people are seeking assistance through Medicaid. Chris spoke about the DSAAPD-funded Caregiver Resource Centers throughout the state with locations in Wilmington, Newark, Dover, and Sussex County. She suggested having these case managers attend a specific training. People call and get information about services across the lifespan. Also, the ADRC (Aging & Disability Resource Center) and 211 Call-In Center could be other groups with which to make a connection. Linda spoke about getting information out in a timely way. Ann commented that we could have information regarding insurance, statewide or countywide, age range, have certification and knowledge of brain injury. Chris stated that Delaware Valley Residential Care is building the new facility and are purchasing Peachtree Acres. Chris explained that they do not use the clubhouse model.

Tammy spoke about reviewing the Priority & Goals. She kept coming back to how we can make informed decisions because we do not have a data base on people with brain injuries. Ann spoke

about splitting into two groups with one working on Priority #1 and another group working on Priority #2. John commented that the Priorities could be worked on simultaneously.

Priority 1: Potential Action Items/Strategies were discussed.

- Provide input about brain injury in the SIM (State Innovation Models) Care Coordination model. Ann commented that this is rolling out now. She added that when they get to the Healthy Neighborhoods, we could ask this group to present at a future meeting. Linda added that the Delaware Center for Health Innovation is no longer the vendor for the Healthy Neighborhood. (The new vendor is Health Management Associates who also works with Mercer Health & Benefits.)
- Improved coordination of existing information systems such as BIAD and ADRC.

Objective 1.2 was discussed: *Facilitate multimedia compilation and accessibility of current, comprehensive information on brain injury support options.* It was noted that there is no funding for this. Ann spoke about doing a small-scale needs assessment. She will look at what she did a number of years ago and will bring it to a meeting for review. John commented that we have limited contractual funding, but will look into available funds. Ann commented that the survey could be very small with two questions asked. Chris spoke about categories of the types of resources. Ann suggested that all members bring this information to give us ideas. Andrew commented that BIAD has had a Resource Directory for many years that could be provided to people. ADRC has a Guide to Services. Suggestion was made to work with them to have a section related to brain injury in this Guide since they already have a data base and system in place. Ann spoke about a booklet called “Connecting the Dots”, which is a good overview. She stated that once information is gathered, we can identify gaps. John suggested that a subcommittee could gather this information from entities and put together it together. It could then be put on the SCPD website. Housing is a huge issue once released from the hospital or rehab center. John commented that there needs to be a breech between traumatic rehabilitation to long term rehabilitation, especially for people with brain injuries. Ann spoke about a common problem with people trying to get assistance through Medicaid and saying their families are taking their money so they can be eligible for Medicaid because private insurance will not cover the services they need. Other issues are that they are far from home getting assisted living with rehabilitation which is paid for by Medicaid and their families want them to be closer. Chris suggested working through Family Shade/Families Know Best (an umbrella organization) to conduct a survey for parents whose children have brain injuries to find out what services they might be lacking. It would be a small group, but might give us additional information. The Priorities will be worked on further.

Missing Members

A revised spreadsheet (handout) was reviewed of current members for updates. He noted that DPH is required to be at the table. He will follow-up with a letter to Secretary Walker and Dr. Rattay. He will also reach out to Dr. Watson (DSAMH), Carolyn Morris (Telehealth Planning), Francis Haggerty (VA Hospital), Amanda Hunter or rep (Beebe Hospital), Tiffany Stewart (Point of Hope). Ann offered to reach out to Nicol Joseph (Highmark Health Options). A new MCO is AmeriHealth. He will also contact LACC or the Hispanic Council (possible new members). John spoke about the importance of having people directly impacted become members of the Committee. Ann spoke about having a protocol in place when we have new members to make sure that they feel welcome

and not afraid to speak up. John spoke about the importance of members consistently attending in order to achieve goals.

TBI Data Base

Ron spoke about his discussion with James Collins (DTI) who referred him to Secretary Walker. Secretary Walker referred him to DIHN (Delaware Information Health Network). Ron distributed a document regarding DIHN. He spoke to Michael MacDonald (DHIN) about Delaware having a TBI data bank and he agreed to work with us. He will invite Michael MacDonald and Angie Keiser (DHIN) to attend the December 4th meeting to find out how information can be obtained from their data base. Ron added that this will be good timing before the legislation session begins in January. There was discussion about the funding of an epidemiologist. All other states have a Registry. John will email a reminder to missing members. We need to have questions ready for this meeting. Andrew suggested that Linda and Chris gather questions based on calls they receive from people asking for assistance and how it would coordinate with the data base. Linda commented that unless brain injury is the primary diagnosis, she does not know how they will get information. Linda said that there is a trauma data base, but was unsure of what type of information is kept.

We can get data from DMMA on the Home & Community-Based Waiver with Peachtree. There was discussion about getting information from the schools. Dale stated that there are 71 students with a primary diagnosis of brain injury (traumatic). There is no way to collect a secondary diagnosis. It was noted that these numbers are underrepresented. Ann stated that we could start getting numbers as a start. Suggestion was made to contact the Child Development Watch Program. We can then take these numbers to a lead agency to eventually apply for a TBI Grant. Many people do not have their primary diagnosis listed as brain injury although head trauma caused their diagnosis. Several examples were given. Having this information would also make a case for agencies looking to expand services.

Other Business

John reviewed the list of people who will participate on this Committee: Ann, Sharon, Andrew, Kristen, Katie, Vanessa and Nancy. After the meeting, this Committee met briefly and decided to meet on Monday, November 27th at the Smyrna Rest Area Conference Room to review the backlog of applications. Policies will be adjusted at this meeting. Thereafter, they will meet briefly before or after the regularly scheduled BIC meeting to review and approve applications.

ANNOUNCEMENTS

Nancy spoke about Lifespan Respite funding available for families can take a break from being a caregiver who do not receive respite hours from other programs. Additional information can be found at www.delrespite.com. It is not financially based covers across the lifespan.

ADJOURNMENT

The meeting adjourned at 4:10 pm.

Respectively submitted,

Jo Singles
SCPD Administrative Specialist
S: bic/nov17min